The doctor as patient: an encounter with Guillain—Barré syndrome

Denise Bowes, MD, CCFP

The author describes the course and treatment of a severe acute illness that began with cranial nerve palsies and ataxia and progressed rapidly to generalized weakness with respiratory embarrassment. There was no sensory loss or elevation of the protein level in the cerebrospinal fluid. The Miller Fisher variant of Guillain-Barré syndrome was diagnosed. At the height of the illness, a period lasting about 2 weeks, the author was almost completely paralysed, retaining only a little motion in some fingers and one foot; she was able to breathe on her own but required suctioning through a tracheostomy, and her eyes had to be taped shut because of her facial paralysis. She remained mentally alert throughout. Proper care of such a helpless patient demands not only excellent technical performance of many nursing procedures but a sensitivity to the patient as a person. The author describes the many shortcomings of the care she received and the value of physiotherapy in her rehabilitation and makes a number of specific recommendations for the care of critically ill conscious patients.

Description par la malade elle-même de l'évolution et du traitement d'une affection aiguë grave qui, ayant débuté par des paralysies de nerfs crâniens et une ataxie, a évolué rapidement vers une faiblesse généralisée avec troubles respiratoires, mais sans anesthésie et sans hyperalbuminorachie. On a donc posé un diagnostic de forme de Miller Fisher du syndrome de Guillain-Barré. À la période d'état, qui dure environ 2 semaines, la malade est complètement paralysée, à quelques mouvements près de certains doigts et d'un pied. Elle respire spontanément mais a besoin de fréquentes aspirations par trachéostomie. À cause de la paralysie faciale on lui a fermé les yeux au moyen de ruban adhésif. Pendant tout ce temps elle demeure parfaitement consciente. Pour bien soigner une malade si démunie, il faut non seulement que l'infirmière possède bien ses diverses techniques. mais qu'on soit sensible aux besoins de la malade en tant que personne. L'auteur décrit les nombreux manques dans les soins qu'on lui a donnés et montre le rôle joué par la physiothérapie dans sa réadaptation. Enfin, elle formule un certain nombre de recommandations concrètes pour le soin du grand malade qui a gardé sa conscience.

I am a 34-year-old family physician with a practice in Athens, Ont. During the summer of 1983 I spent 12 weeks in hospital with Guillain-Barré syndrome. Although the illness is rare, affecting 1 to 8 individuals per 100 000,1.2 the symptom's, signs and feelings I experienced were similar to those in much more common neurologic problems, such as stroke, multiple sclerosis and brain tumours. I will describe the onset, treatment, progression and residual effects of the syndrome as well as signs of recovery and steps in rehabilitation. Also, I learned a lot about being a patient, information I hope to share with other physicians through this article. All of my criticism is intended to be constructive.

In some ways my illness was made easier by my having a medical background. I could understand the terminology, participate in relevant discussions and sometimes influence decisions about my care. I was familiar with Guillain-Barré syndrome, though not with the Miller Fisher variant³ of ophthalmoplegia, ataxia and areflexia, which was how my illness began.

In other ways being a doctor was a handicap. I thought of the worst possibilities of differential diagnosis and, for several days, did not believe that I had Guillain-Barré syndrome. I was aware of errors in treatment (e.g., conflicting medications) and omissions in my care (e.g., skin care, bowel routine), an awareness that increased my fear and frustration.

Initial features of the illness

History

Three weeks before becoming ill I diagnosed Guillain-Barré syndrome in a patient in the emergency department of the local hospital. I was in excellent health at the time and remained well for the next 11 days. Then I contracted an upper respiratory tract infection with left maxillary sinusitis, which was treated with amoxicillin. Nine days later I began to notice a pins-and-needles sensation in my tongue that lasted for about 10 minutes after eating; my sense of taste was not impaired. The next night — the night before I was admitted to hospital - I noticed mild ptosis of my left eyelid and, later, the onset of horizontal diplopia in all directions of gaze except downward. By morning I had

Reprint requests to: Dr. Denise Bowes, Athens Medical Centre, PO Box 158, Athens, Ont. K0E 1B0

mild ataxia. During the day the pins-and-needles sensation also developed in the tips of my fingers and spread to my palms; later it appeared in the soles of my feet. My gait was slightly unsteady and broad-based, and tandem gait was poor. A headache with photophobia appeared that lasted for several hours. I was very frightened.

Several years previously I had had two episodes of viral pneumonia, but neither I nor my family had any history of neurologic illness.

My diet was nutritious, and I rarely drank alcohol. At the time, besides the amoxicillin, I was taking oral contraceptives. My immunization record was up to date.

Results of physical examination

At the time of admission I was afebrile, normotensive and fully conscious, with a normal mental status. My corrected visual acuity was 6/6. My fundi and visual fields were normal, and my pupils reacted equally to light and accommodation. There was no nystagmus. There was ptosis of my left eyelid and reduced upward gaze of the left eye, a sign of partial palsy of the third cranial nerve with pupillary sparing. I could sustain an upward gaze. I had bilateral partial palsy of the sixth cranial nerve but normal function of all the other cranial nerves. I had normal muscle tone, bulk and power except for a mild decrease in the power of my abdominal muscles. My gait was ataxic, but I was able to perform other cerebellar and extrapyramidal tests normally. Despite my previously having had hyperreflexia, the biceps reflexes were the only ones in my limbs that could be elicited, and only with reinforcement. My abdominal reflexes were diminished equally in all four quadrants. I had no sensory loss. I was told that I had Miller Fisher syndrome.

Laboratory findings

The hemoglobin level, hematocrit, and total and differential leukocyte counts were normal, as were the opening pressure, clarity, cell counts, levels of glucose and protein, and oligoclonal banding of the cerebrospinal fluid. Culture and sensitiv-

ity and antibody tests excluded infectious mononucleosis and infection by streptococci or spirochetes.

My tidal volume was 0.46 L, vital capacity 3.9 L and maximum inspiratory volume in 1 minute (V₁ max) 12.9 L.

X-ray films of my skull and computer-assisted tomography (CAT) scans of my skull and brainstem showed no abnormality.

The syndrome

There has been much debate in the literature about the relation between the triad of signs described by Miller Fisher — ophthalmoplegia, ataxia and areflexia — and classic Guillain-Barré syndrome.4-7 Is the former a variant of the latter, or are they the same entity? In my case what appeared to be classic features of Miller Fisher syndrome developing over 3 days progressed to a generalized bilateral motor weakness consistent with Guillain-Barré syndrome.8,9 There has also been disagreement about diagnostic criteria.8.9 Munsat and Barnes4 summarized the possible explanations for ataxia in the absence of sensory loss; no cerebellar changes have been demonstrated pathologically. Richter,10 however, presented evidence of spinocerebellar tract degeneration in the spinal cord. Loffel and associates," who observed 123 patients with Guillain-Barré syndrome, reported that 44% showed signs of cranial nerve dysfunction; the nerves most commonly affected were the 7th, 9th and 10th. They also described a recurrence rate of 3.3% (4 in 123) by 8 years after complete recovery.

The disease is produced immunologically, either by a circulating myelinotoxic IgM antibody or by a cell-mediated process of delayed hypersensitivity in genetically predisposed individuals following exposure to a virus that has not been identified.⁵ An increased amount of protein in the cerebrospinal fluid despite a normal cell count is part of the classic picture, although a normal amount of protein is often seen early in the disease, as in my case.

Progression of the illness

In my case steroids were with-

held, as their use has not been demonstrated to be helpful either in reducing the severity of the disease or in reducing residual signs. Plasmapheresis is being reserved for chronic cases. Is was glad to be allowed to recover on my own, without steroids, as with my history I was liable to contract pneumonia and did not want to increase the risk of that.

By the evening of my second day in hospital my trunk and neck muscles were weakening, so that it was difficult to turn over in bed. I was told that the weakness came from lying in bed, but I knew better. Ophthalmoplegia had become complete for upward and horizontal gaze, though I could gaze downward a few degrees. No convergence was possible. Bell's phenomenon was present bilaterally. My pupils reacted to light equally (directly and consensually). My facial muscles weakened slightly. My gag reflex was reduced bilaterally, as was palatal elevation. My speech began to slur slightly, and I had difficulty swallowing solids and, later, liquids.

My voice became weaker. Proximal muscle groups became very weak and distal groups even more so, such that only jerky movements were possible. The right side was slightly stronger, but I am righthanded. Neck flexion and extension were profoundly weak: when I was propped in a sitting position to drink, my head flopped over. Sensation was normal when tested, although the paresthesia continued. I was areflexic. By day 3 I was unable to feed or care for myself, and I felt helpless. I feared being an invalid permanently and really doubted the diagnosis. My doctors did the right thing — they came and explained that they were not hiding anything.

Aching in my back and neck developed because of immobility. For neck support I asked for a cervical collar but was told by nursing staff that I could not get one until the physiotherapy department opened 3 days later (it was Friday of a long weekend). I began to feel angry about the "rules"; I suspected that the emergency department stocked cervical collars and that one could be had if the nurses tried.

As clinical clerks and interns, my peers and I had joked about the

worst time to be a patient in hospital — July 1 — and there I was, admitted in late June and going downhill rapidly. By July 1 I had a new team of house staff.

When I became dehydrated after a CAT scan the new clinical clerk came to start intravenous rehydration. He put a tourniquet on my arm and began tapping the volar aspect of my wrist. I started wondering why we don't give students some training in these procedures before sending them onto the wards. I told him what to look for and suggested that he get help if he could not see a vein that looked easy to hit. The resident on call assured me that she had just completed a rotation in the intensive care unit and could start an IV on a rock. I was not a rock. It took two tries, a preview of what was to come.

That evening my respiratory function was checked; the blood gas values were normal, but my tidal volume was 0.3 L, vital capacity 2.0 L and V₁ max 4.0 L. I could no longer press my call bell. I was alone, getting worse and afraid to go to sleep.

I had not been turned and had not received any skin care other than being given an "egg-crate" mattress. My first few experiences using a bedpan had resulted in my buttocks' lying in the shallow "slipper" pan, getting wet and not being dried by the nurse. I could not dry myself but felt unable to say anything about it. When I was moved to the intensive care unit that night after midnight I was relieved.

The painful poking to establish an arterial line began. I found self-hypnosis useful during such painful procedures. A close friend arrived later to see how I was adapting to the move and noted the care I was getting in the intensive care unit. He gave me a lot of encouragement despite the worsening of my condition.

Over the next few days almost complete facial nerve palsy developed. Because I could not close my eyes completely they were lubricated and taped shut, with Micropore tape, every 4 hours — a procedure that continued for several weeks, until I could open the lids; then my eyes were taped shut only at night. Many methods of applying ointment

and taping were tried. A simple, effective approach was to apply a small amount of ointment to the lower-lid conjunctiva, then to place about 4 cm of tape diagonally from the upper lid to the cheek bone. Untaping from top to bottom minimized the possibility of corneal injury. Patching did not work well: the eyelid sometimes opened under the patch, with a risk of corneal abrasion and ulceration. Applying ointment to the outside of the lids or to the underside of the upper lid was not acceptable. Paper tape proved difficult to remove and added to the unavoidable irritation from frequent taping.

My gag reflex was absent, speech soft and slurred, and tongue very weak. I had great difficulty coping with mucus, which gathered in large amounts in my throat or nose, depending on my position. I seemed unable to swallow, and for about 2 days I tried to spit it all out. Then began almost continuous suctioning, which was exhausting and very irritating to my throat and nose.

By this time I understood that hospital personnel can be divided into those who cause pain and those who don't.² For example, some nurses have a way of gently placing the tip of a suction catheter into the areas on either side of the midline of the pharynx and quickly extracting mucus, whereas others fish around, rarely get to the critical areas and cause a lot of discomfort.

I was afraid to sleep when I had a nurse who did not want to stay in my room and to be available to clear the mucus. If she preferred to sit just outside the door writing, I would be terrified. I felt that a nurse who gave the most complete written reports gave the poorest bedside care, and I appreciated one who was with me constantly and wrote only a sketchy note at the end of the shift, giving, instead, a complete verbal report

Important information that was always part of the report in the intensive care unit (but, unfortunately, not in other units) included how to position and turn me, what devices to use where (sandbags, pillows, donuts, splints) and what areas were painful, so that I would not be lifted or turned by these areas. The reports also provided simple hints,

such as to use an incontinence pad under the bedpan because I usually passed a large amount of urine that sometimes spilled or overflowed.

After about 3 days in the intensive care unit wiggling my fingers and moving my ankles laterally were all I could do. I had foot drop, and almost every nurse suggested foot splints. The physiotherapist noted that my paralysis was flaccid, not spastic, and that manipulating my ankles should eliminate the need for splints. Also, splints were likely to cause pressure sores and would increase the number of devices to which I was attached. I already had an IV line in my right arm and an arterial line in my left wrist, which had a splint to prevent flexion. In the right side of my chest was a subclavian line for total parenteral nutrition, which would often stop running if I was not positioned just right.

After a week in the intensive care unit, when my vital capacity fell to 1.3 L, an endotracheal tube was inserted orally to prevent aspiration of secretions. Later I coughed out the tube, and another was inserted. this time nasally — just when I had started getting used to the feeling in my throat. Both tubes were inserted with a minimum dose of a shortacting analgesic, fentanyl citrate, so as not to decrease respiratory capacity and make mechanical ventilation necessary. After 2 days a tracheostomy was performed under general anesthesia. I was grateful to be free of the discomfort from the tubing.

I worked out a signal system with the nurse, wiggling my radial fingers and thumb to communicate needs: right thumb, turn me; right index finger, provide suction; right middle finger, relieve my pain; left thumb, I need a bedpan; left index finger, wind the head of my bed up or down. Despite having such limited communication I could hear quite well, was mentally alert and slept little. It was extremely frightening to be unable to communicate when I was in danger. I was receiving vitamin K weekly to supplement my parenteral nutrition, but the second time it was given I was also being given subcutaneous heparin twice a day to prevent thromboembolism. When a nurse cheerfully said "Here is your heparin and your vitamin K"

I had no way of saying "Don't give them together".

I was determined not to need ventilation, and willpower may have kept my vital capacity greater than 1 L. A year before, a patient of mine had gone into cardiorespiratory arrest while undergoing ventilation with a respirator whose alarm had been turned off; he had become comatose and died. I was frightened of the same thing happening to me. All around me I could hear nurses complaining about the alarms of ventilators that went off constantly; sometimes they turned these alarms off. The respiratory therapists gave me much encouragement while I was blowing into their measuring devices. A theme developed by Cousins¹³ in "Anatomy of an Illness" is the power of the mind over physical illness. I felt that very much with respect to keeping myself off the ventilator. I also felt a greater awareness of who and what was important to me.

By day 7 in the intensive care unit I had a staphylococcal urinary tract infection, which was treated intravenously with cloxacillin.

Recovery

By day 10 of the illness my right quadriceps and left arm were beginning to regain strength, and I could tolerate small ice chips orally. On day 18 I was transferred to a neurosurgical intensive care unit because it was apparent that I was not going to need mechanical ventilation. Now my pupils were small, though equally reactive to light. My eyes were divergent (no convergence was possible), and only slight elevation with eye closure and slight abduction were possible. There was bilateral ptosis, the eyelids remaining open 2 mm unless taped shut. The sensory function of the fifth cranial nerve was normal, but there was paralysis of the masseters. My facial nerves had partially recovered, so that I could move my lower jaw. My hemoglobin level dropped to 92 g/L (it had been 130 g/L when I was admitted) because of frequent blood tests.

I began to take clear fluids and, later, high-energy full fluids to substitute for total parenteral nutrition when my subclavian line became blocked. I could not move semisol-

ids, such as pudding, cream of wheat and ice cream, to the back of my mouth for several weeks. I learned later from the speech therapists that I could have benefited at that point from exercises that help patients learn to swallow again.

My eyes were still being taped, and being unable to see added to my feeling of isolation and dependence. I had to count on the patient in the next bed or the nurse to notice me moving my hand to attract attention. I was reassured when touched but found it extremely painful. I depended on new people to introduce themselves, as I could recognize people only by their voices.

I learned how much importance a patient puts on the few minutes a day with the doctor, thinking "I must remember everything I have to say; I will not have another chance until tomorrow". When a consultant was due and did not come until 2 days later I became very impatient. The doctors, however, were always encouraging, telling me that I would get better in time. That was exactly what I needed to hear.

The physiotherapists took on enormous importance to me. They noted slight changes in active muscle strength and were as excited as I. They understood how to position and lift in ways that would not harm hurt. Communicating these things to my nurses and to my visitors was important. Most of my nurses seemed unsure of their skills in physiotherapy, but because staff physiotherapists have time to visit only once or twice daily nurses must be able to do the rest. They need more inservice training so that they learn the principles and procedures of physiotherapy. For instance, they were reluctant to stretch my muscles and joints to the point of resistance, as this was painful for me.

Nursing care was fragmented. In the intensive care unit, nurses care for different patients every shift. On the ward, however, they may have the same patient for 2 days or nights in a row. Although the variety reduces stress for nurses, it requires that they learn patients' needs anew every time they go to work and provides no continuity for the patient. As Cousins¹⁴ stated, "for most people the facts of hospital life involve discontinuity, fractioned care,

and inadequate protection against surprise. People come and go; you make your adjustments as best you can."

As my active muscle movement began to increase, aching developed in every muscle. This was most severe at night, keeping me awake. Like learning a new sport and using muscles that have not been used, it hurt. I needed analgesics and was afraid to take narcotics constantly. I took liquid Tylenol during the day and had codeine injections at night, but I had to request these and felt guilty asking for codeine. I would have preferred receiving Tylenol automatically every 3 hours, as should be done in cases of chronic pain, but the nurses never gave it to me unless I asked. When I did active range-ofmotion exercises two or three times a day and had similar passive exercises every 2 hours I suffered much less pain. The exercises seemed far more helpful than did the analgesics.

A week later, when I was transferred to the neurology ward, my cranial nerve functions were improving, as were most of my muscle groups. My breathing was also improving, and, though still functionally blind, I could print and play charades to get my message across. The recipient of my written message had to move my hand to a blank area of the page so that I would not write over other words. If I had to write a message twice I became angry from the frustration and effort.

I had to restrict my visitors, as I tired easily. This was awkward because there were several close friends I wanted to visit with who would call ahead to see if they could come at a certain time. If I was expecting them I would have to turn down other visitors so that I could save my strength for physiotherapy. Many well intentioned patients of mine were turned away. I often felt guilty about sending out a message that someone could not come in.

After I had been on the ward about 1 week, a severe headache developed that lasted 2 days. I eventually recognized that it was caused by my anger and frustration at being ill and dependent. Although I could swallow liquids, I still had to be fed by a syringe, as I could not

suck through a straw or drink from a cup. However, a device was set up that allowed me to control a fan and a radio with a lever.

All the fear of dying that I had suppressed while critically ill began to come out. I was afraid when left alone and dreamed that a man came into my room and shot me. Fire alarms went off several times, and I was terrified of not being able to get out of the hospital if there was a fire. Writing my feelings and sharing them with a psychiatrist whom I could trust helped, as did being reassured that the feelings were normal.

I fantasized that I looked either grotesque or like an expressionless blob, fantasies contributed to by a nurse's comment in the intensive care unit: "You wouldn't want to see yourself now." A friend assured me that I still looked like myself, and a mirror provided confirmation.

Visitors were becoming important to my recovery, especially those whose attitudes were positive, who pointed out improvements and who were encouraging. I appreciated hearing news from home and was relieved to hear that the rest of the world was going on normally. News does not have to be exciting. I lived vicariously through hearing about the everyday activities of friends and their families. The monologues required some thought and planning

by my visitors. Receiving good wishes from patients and friends in the form of cards was something I looked forward to. When I could open my eyes I still could not read because of diplopia.

Some visitors performed helpful functions, like rubbing sore muscles, doing passive physiotherapy and giving me a drink through a syringe, as well as reading to me. A dentist friend brushed and flossed my teeth on her visits and arranged for someone else to do so daily when she could not be there. I found this very important to my sense of well-being as I had previously had gingival problems that necessitated meticulous care. Many nurses seemed to think mouth care consisted of running a gauze square dipped in mouthwash over one's tongue. How many doctors ensure that disabled patients have their teeth brushed and flossed regularly?

One of the most helpful visitors I had was a woman who had recovered from Guillain-Barré syndrome. The timing of her visit was important. I felt ready to talk to someone who had experienced what I had come through. She had fully recovered and was again leading an active, energetic life, but it had taken more than a year for her endurance to return. I began to plan for realistic changes in my lifestyle and in my practice. She told me how she had,

for some time, feared catching a cold, and her forewarning allowed me to keep my own fear in perspective.

There were several aspects of medical care that bothered me. New residents doing procedures on patients, especially in the intensive care unit, should be supervised by a staff doctor who can tell the resident what to do each step of the way.

While on the ward, I was visited by large groups of doctors and medical students on rounds. I often had no idea who most of the students were. I felt like a fish in a fishbowl, being stared at by a group of strangers while one or two doctors talked to me and I wrote in response. If they had introduced themselves, it would have helped; if there were too many to introduce, then there were too many to come into my room.

The ordering of tests without previous physical examination annoyed me. For example, although the physiotherapist listened to my chest every day because of the risk of pneumonia, the house staff did not listen to my chest but ordered a chest x-ray examination while I was on the ward. I had had my chest examined radiographically several times while in the intensive care unit. I did not have a cough, sputum or respiratory distress, and when my tracheostomy cuff was inflated my ability to cough was stronger. I did not feel unwell and was afebrile, so I refused to have the x-ray examinations.

Constipation became one of my greatest problems. I lost count of the times I became impacted from weeks of being on a liquid diet that included a large quantity of milk products and a supply of liquid iron. Liquid Colace (docusate sodium) did not help and tasted so bad that after 2 weeks of it twice a day I began to vomit after every meal that included it. A routine of suppositories every 2 days and, when this regimen was not effective, a small dose of a laxative or an enema was established. Once I was able to eat bran for a few days I needed no other stimulants. But by then I was on the rehabilitation ward, where nurses are used to monitoring bowel routines: I was awakened at night to be asked if I would like a laxative or in the morning to be asked if I needed a suppository.

Principles of hospital care for all seriously ill patients:

- Establish early and continuing communication among all members of the health care team about the patient.
- Re-examine the patient frequently.
- Reduce the frequency of routine tests as soon as possible.
- Review and update orders, cancelling unnecessary ones, especially before transferring a patient.
- Order analgesics to be administered regularly for chronic musculoskeletal pain, as for chronic pain caused by cancer.
- Review with nursing staff aspects of required skin care, mouth care, bowel routine and physiotherapy.
- Call on a member of the psychiatric team or the patient's family doctor to help the patient ventilate his or her feelings.
- Refer early to a speech therapist the patient with dysphagia or dysarthria.
- Show the critically ill patient his or her reflection in a mirror to maintain the body image.
- Bring in a visitor who has recovered from the same illness to discuss the events with the patient and his or her family.
- Maximize a patient's chance to take advantage of medical rounds by asking: "Is there anything else you'd like to ask?"
- At the beginning of each visit introduce yourself to the patient who cannot see you and touch the patient to communicate concern.
- Introduce all students and staff who participate in visiting and caring for the patient.

Rehabilitation

As my motor function increased I learned a great deal about rehabilitation.

I could not believe the profound weakness I felt the first time I sat in a chair: tipped back and feet elevated, I still felt dizzy and weak after about 15 minutes. I learned to use a transfer board to get from bed to wheelchair without help, and this was much better than being lifted by two or three people. After a short time in a semireclining "Cadillac" chair I went on to a wheelchair with head support, which, after a few weeks, allowed me to be wheeled outside. It seemed that after every advance I needed enormous amounts of sleep.

I was introduced to a tilt table to help me stand. When I was tilted upright, strapped to the table, my blood pressure was expected to drop but rose very high instead; I felt I could not do anything right. Soon, though, I could move to a chair without the transfer board and had a chance to try standing in the parallel bars, and, later, walking with a rollator walker, which does not have to be lifted with each step. Patients who have been unable to walk feel special gratitude to physiotherapists for helping them regain the independence that walking gives.² The first steps are emotional: painful memories flooded back to me, yet I felt that I was leaving them behind, symbolically walking away from a bad experience. When I could walk, there was no longer any ataxia present.

At the same time, swallowing and fine motor coordination recovered, and I continued to try to do as much as possible for myself in order to become independent again. My diplopia resolved gradually, disappearing for a few hours a day, until it was completely gone at 18 weeks after onset.

Dysarthria remained a major problem for several months, resolving eventually with speech therapy: frequent repetition of difficult sounds and facial exercises to strengthen weak muscles. Six months after the onset of my illness my speech, although slow, had returned to 98% of normal in articulation.

Occupational therapy helped me become more realistic about my capabilities in activities of daily living.

Residual effects

To date the only indication of muscle stretch reflexes is a slight flicker at the knees during the Jendrassik maneuver. A small abnormality accompanied the return of facial innervation: my right eye partially closes when I smile widely, and the right side of my mouth turns up when I close my right eye.

Residual signs were present in 39 (32%) of 123 patients with Guillain-Barré syndrome studied by Loffel and associates. At follow-up an average of 5 years later, absent reflexes and motor weakness, mainly distal in the legs, were the commonest residual signs. The authors observed that patients with the most severe limb paralysis had the greatest likelihood of residual effects. Also, the time between maximal manifestation of the syndrome and the first signs of recovery was correlated with the frequency of residual signs.

My muscle power is 4+ to 5, but my endurance remains poor. I have no foot drop, thanks to passive dorsiflexion. When I get overtired the diplopia recurs. I don't yet feel emotionally ready to treat patients with similar problems. Before discharge from hospital I visited the intensive care unit and felt frightened by the sound of the respirators.

What complex functions human bodies perform! Learning to see, to swallow, to use my hands, to sit and to walk again as an adult made me appreciate the abilities I had taken for granted so long.

I thank all those who helped me survive and recover.

I am grateful to Dr. Martin Bass for his helpful comments and to many other colleagues and friends for their encouragement and comments about the early drafts of the paper.

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